MODEL SCHOOL HEALTH INFORMATION SYSTEM

FINAL REPORT

Division of Science, Education and Analysis

Maternal and Child Health Bureau





Maternal and Child Health Information Resource Center

Model School Health Information System Project Final Report

Prepared by:

Massachusetts Department of Public Health Bureau of Family and Community Health Office of Statistics and Evaluation

March 1998

Grant No. MCJ-25D401

Prepared for:

Division of Science, Education, and Analysis Maternal and Child Health Bureau, HRSA, PHS, DHHS Parklawn Building 5600 Fishers Lane Rockville, Maryland 20857

ACKNOWLEDGMENTS

The Bureau of Family and Community Health of the Massachusetts Department of Public Health would like to acknowledge the following groups whose efforts contributed to the development and implementation of the Model School Health Information System (MSHIS):

- The Massachusetts Department of Education (MDOE)
- MSHIS Local Site Planning Groups
- MSHIS Region I Advisory Committee
- MSHIS Technical Committee
- MSHIS Steering Committee
- MSHIS Confidentiality of School Health Records Committee
- The MSHIS project could not have been implemented without the participation of the administration, staff, and particularly the school nurses from the pilot demonstration sites.
- The Bureau would particularly like to acknowledge the Maternal and Child Health Bureau, HRSA, United States Department of Health and Human Services, which provided the funding for the Model School Health Information System.

Finally, we would like to acknowledge the following individuals who were essential to the writing and review of this document: Sion Kim Harris, Karen Adler, Dorothy Kelly-Flynn, Sabine Hedberg, Deborah Klein Walker, Marlene Anderka, Anne Sheetz, Kathy Atkinson, and Lise Zeig.

To obtain additional copies of this report, contact the Office of Statistics and Evaluation, Bureau of Family and Community Health, Massachusetts Department of Public Health, 250 Washington Street, 5th Floor, Boston MA 02108. Telephone (617) 624-5536.

TABLE OF CONTENTS

I. I	PROJECT SUMMARY	1
	A. Project Goal and Objectives	1
	B. System Design	2
	C. Project Accomplishments	3
II.	PROJECT DEVELOPMENT	4
	A. Key Participants	4
	B. Guiding Principles	
	C. Uniform Health Dataset (UHDS)	
	D. Technology Options	9
III.	. CONFIDENTIALITY, PRIVACY AND DATA SECURITY	12
	A. Confidentiality of School Records	12
	B. Permanent Student Identification Code	13
IV.	PILOT SITE IMPLEMENTATION	14
	A. Pilot Site Selection and Implementation	14
	B. Data Collection, Analysis and Reporting	
	C. Pilot Site Evaluation	16
v.	OVERALL PROJECT EVALUATION	18
	A. Overview	18
	B. Success In Achievement Of Objectives	
	C. Recommendations for the Future	
	D. Feasibility Of MSHIS	
	E. Conclusions	22
VI.	AVAILABLE SUPPLEMENTAL DOCUMENTATION	23
VII	I. APPENDICES	24
	Appendix I Key Participants	
	Appendix II UHDS Version 2.0	

PROJECT GOAL AND OBJECTIVES

The primary goal of the Model School Health Information System (MSHIS) initiative was to develop a prototype school health information system capable of standardizing school health data collection across states, reporting health status data and school health service use from grades K-12, and testing the feasibility of using a unique identifier in establishing an epidemiological database. Such an information system would permit data analysis for the purpose of needs assessment and program monitoring, planning and evaluation at state and local levels. The collection and monitoring of data on children and youth in school is an important component of program and policy development for improving the health and well-being of all children and youth. It is thought that a child's ability to learn is directly influenced by his or her health status; improving health is likely to enhance educational achievement.

The Massachusetts Department of Public Health (MDPH) received a three-year grant from the Maternal and Child Health Bureau of the United States Department of Health and Human Services to develop and pilot test a computerized school health information system designed to identify and monitor child health status indicators and assess the feasibility of linking those with educational achievement. With this grant, the Bureau of Family and Community Health within the Massachusetts Department of Public Health, in collaboration with the Massachusetts Department of Education (MDOE) and departments of public health and education in the other New England states (Region I), developed a prototype Model School Health Information System. In developing the MSHIS, a broad and comprehensive definition of health based on the CDC model of comprehensive school health services was adopted.

Specific *PROJECT OBJECTIVES* in developing the MSHIS included:

- Creating local commitment, and interagency and interstate collaboration:
- Developing a standardized set of data elements reflecting the health status of children and youth to be collected through local school districts;
- Establishing and implementing pilot sites; and
- Planning for a statewide data collection system.

This project represents a convergence of the fields of public health, education, and technology in this first effort to develop a school health information system. While portions of the project could not be completed due to time constraints, many valuable lessons were learned during the development and implementation phases of the MSHIS. These lessons will guide the future development of the MSHIS in Massachusetts.

SYSTEM DESIGN

The MSHIS system was designed to collect individual student health information at the local school level. After data collection by the schools, the system called for transferring the information to a Central Repository at the Massachusetts Department of Public Health where it would serve as a database. The structure of the MSHIS system, therefore, includes three components:

MSHIS SYSTEM COMPONENTS

- A local school health information collection and management system.
- An MSHIS Electronic Data Interchange Standard.
- A computerized Central Student Health Data Repository (CSHDR).

As originally conceived, the MSHIS system was designed to collect 1) data related to socio-demographic, health status and environmental measures, and 2) behavioral risk, service utilization, and education indicators. (For more information on the data collected, please see the section on the UHDS.) It was anticipated that data collected under the MSHIS would be used for the following purposes:

DATA COLLECTION USES

- Conducting local, state and national needs assessments
- Monitoring state-mandated programs and screenings
- Monitoring compliance with Title V reporting and other federal data requirements
- Directing program planning, management and policy development
- Assuring follow-up services after problem identification
- Conducting process and outcome evaluations

While the UHDS was originally intended to consist of individual-level information, in the process of developing the dataset, confidentiality issues became a major concern. In order to accommodate concerns regarding confidentiality, the pilot version of the UHDS was revised to collect only aggregate data at the central repository and was tested in six demonstration sites beginning in September of 1994.

PROJECT ACCOMPLISHMENTS

Based upon its original objectives, the project was considered to be successful in a number of areas. Its *MAJOR ACCOMPLISHMENTS* are as follows:

- Establishment of the MSHIS Region I Advisory Committee;
- Establishment of the MSHIS Technical Team for system design and development;
- Development of the Uniform Health Dataset (UHDS);
- Development of Principles for System Development;
- Provision of technical assistance to local school districts across the country;
- Establishment of six functioning pilot demonstration sites;
- Establishment of the UHDS Data Transmission Standard to guide electronic transmission of UHDS from school districts to MDPH;
- Identification of six levels of data analysis and aggregation and implications for data collection and reporting;
- Establishment of partnerships with software developers and computer hardware manufacturers;
- Identification of new technologies which are applicable to the MSHIS;
- Establishment of the Confidentiality of School Health Records Committee; and
- Development of local survey tools for use in data collection by the schools.

KEY PARTICIPANTS

Development of the project was accomplished through the collaboration of several groups and committees including the MDPH Project Management Team; the Massachusetts Steering Committee; the Region I Advisory Committee; the MSHIS Technical Team; and the Confidentiality of School Health Records Committee. Please see **Appendix I** for a description of each group's function.

GUIDING PRINCIPLES

The Principles for System Development, which are the core values directing prototype design, were developed by the MSHIS Technical Team and refined by the Region I Advisory Committee and the Confidentiality of School Health Records Committee. These principles address issues of confidentiality, data element justification, quality assurance, cost-effectiveness, resource levels as well as other issues. The MSHIS **PRINCIPLES FOR SYSTEM DEVELOPMENT** are as follows:

- 1. All data elements included in the system should be justified for inclusion and their definition, use and who has access must be clearly defined.
- 2. Safeguards should be built into the system to protect confidentiality and rights to privacy and to address the requirements of freedom-of-information mandates. Personally identifying data should be retained only at the local level and only with strict confidentiality protections.
- 3. Safeguards should be built into the system for quality assurance purposes including safeguards for data integrity (e.g. errorproofing), initial and ongoing centralized training, and staff development.
- **4.** All school buildings in a district should be able to participate in the system.
- 5. Local access to information is critical to efficient management and evaluation of school health programs as well as timely billing. Data from the MSHIS should be available at local sites to permit timely and efficient report generation.

- **6.** Cost should be considered when alternative data collection, analysis, transmission and report generation capabilities are considered for implementation.
- 7. Training requirements and ease of implementation should guide system development.
- 8. Computer system design should build on and work with existing technologies at the local level. Given that some schools have made significant investments in hardware and software, offering a range of compatible technical options seems logical.
- **9.** At a minimum, MSHIS participating schools using automated systems will need to provide the following:
 - a) Local technical assistance capable of supporting hardware, software and on-site consultation.
 - b) Procedures to assure appropriate ongoing transmission and storage of data.
 - c) System staff knowledgeable about the nature of the data.
- 10. System development should include plans to improve inter-school coordination within a school district and intra-school coordination among all staff involved in comprehensive school health.
- **11.** Pilot demonstrations should be replicable by other locations within the region.

UNIFORM HEALTH DATASET (UHDS)

1. Data Collection Options

In developing the MSHIS and the UHDS, six *DATA COLLECTION OPTIONS* were considered. A brief description of each follows:

Aggregate data collection: Rates at the school system or school building level.

Cross-sectional data collection: Collection of anonymous unidentified individual-level data. In this option, the central repository stores specific values for each data element for each student, but does not identify the student associated with the data. Data collected through this option could be used for tracking status over time.

Local longitudinal data collection: Collection of individual data with identifiers assigned by the school district. Under this option the Central Repository will not maintain continuity in a student's health data if a student moves from one district to another.

Closed longitudinal data collection: Involves collection of anonymous, securely identified individual data. Under this option, the Central Repository stores specific values for each student and labels data with a secure private identifier that stays with the student even if he or she moves.

Open longitudinal data collection: Involves anonymous data identified with public identifier (social security number, etc.).

Hybrid data collection: A combination approach.

In considering these options, the Region I Advisory Committee determined that the ability to track students over time and across schools was an important feature. The Committee believed that, ideally, an attempt should be made to create a longitudinal database that would allow for monitoring of child health outcomes and examining of relationships between key outcomes and developmental changes over time. However, given that at the time of the study, questions and concerns about confidentiality had not yet been addressed in a longitudinal database electronically submitted from schools, MDPH chose to collect only aggregate data in the pilot communities.

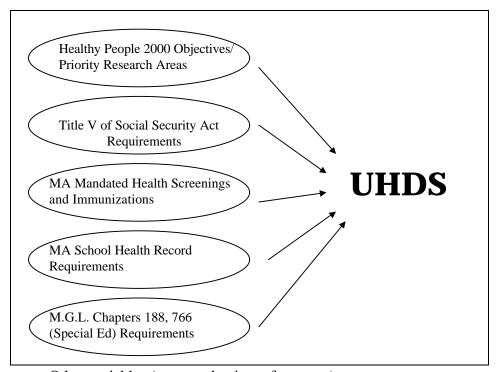
2. Development of the UHDS

The UHDS defines what student health data is to be collected as part of the MSHIS and how that data is to be coded. It covers a comprehensive set of indicators relating to each student's health status, service utilization, sociodemographic background and related data, and includes definitions for each data element and its purpose.

In the process of developing the Uniform Health Dataset (UHDS), the Region I Advisory Committee reviewed many child health status survey instruments and questionnaires developed over the past twenty years. In addition, summary documents were developed from the Title V reporting requirements of the Maternal and Child Health Services Block Grant. The requirements from these documents, as well as the Healthy Children 2000 objectives, were reviewed and considered in the development of the UHDS. When applicable, UHDS data collection justification includes citations from the following sources:

The *UHDS INDICATORS* can be grouped into seven categories:

- Demographic variables (e.g., mother's education level);
- Access to care measures (e.g., child's usual source of health care);
- Environmental variables (e.g., type of school health program);
- Health status indicators (e.g., screening for weight/height);
- Health care utilization measures (e.g., health screenings received);
- Injury indicators (e.g., type of injury); and



• Other variables (e.g., academic performance).

3. UHDS Versions

a. UHDS Version 2.0: After reviewing resource documents and considering the advantages of including various measures and indices, an initial UHDS was created. The data elements, preliminary definitions and measurements contained in the initial UHDS were developed from discussions with the Region I Advisory Committee, the Massachusetts Steering Committee, state-specific meetings and interviews with professionals in the field of comprehensive school health at both the state and local level. Based upon additional discussions with the Region I Advisory Council, the Massachusetts Steering Committee and school health professionals, the UHDS was revised and a UHDS Version 2.0 was

generated for use as the dataset for pilot-testing. (See Appendix II for more detailed information regarding the UHDS Version 2.0.)

The linking of data from MSHIS to other health data systems was not considered due to differences between health and education-based information systems and unresolved issues related to confidentiality and right-to-privacy.

b. Aggregate UHDS Version: Due to parental concern regarding confidentiality and data security, only aggregate data was collected during the pilot phase of the project and no identifier that could be linked to an individual student was included. MSHIS pilot data does not permit individual-level data analysis or linkage. While not as informative as individual-level data, aggregate data can still be used to develop state-wide statistics on a variety of student health status indicators, meet important reporting objectives for state and federal contracts, and determine the impact of some public policy issues. MDPH will continue to explore options for assuring confidentiality so that a longitudinal database on individual students may be maintained and used to monitor overall child health status over the school years.

The Aggregate UHDS Version represents a modification of UHDS Version 2.0 and consists of selected individual-level data elements converted to data aggregated by district and race, ethnicity and gender groups. In the pilot phase, aggregate MSHIS data collected from schools was to be shared with MDPH for years K, 2, 4, 7, 10 and 12. Some examples of the aggregate data collected include the following:

SELECTED ITEMS IN THE UHDS

- Number of students having annual physicals outside of the school
- Number of students passing vision, hearing, and postural screening tests
- Number of students fully immunized at school entry
- Number of students not fully immunized at school entry
- Number of students exposed to environmental tobacco smoke in the home
- Number of students in various height/weight categories (i.e., high weight for height, low weight for height)
- Numbers of students with various types of health insurance coverage

4. Core Data Items

Amongst the data elements in the UHDS, ten core areas were deemed particularly important for Massachusetts data collection. *CORE AREAS FOR DATA COLLECTION* include the following:

- **1.** Immunizations;
- 2. Mandated screening tests (vision, hearing, postural screening);
- **3.** Annual physical examination;
- 4. Health conditions;
- **5.** Health insurance coverage;
- **6.** Visits to nurse by type of visit;
- **7.** Assistive devices;
- **8.** Medication administration;
- **9.** Injury activity, body part and type of injury; and
- **10.** Massachusetts Tobacco Control measures.

The specific definitions and justification for all of the UHDS data elements can be found in Appendix II.

TECHNOLOGY OPTIONS

1. Hardware

In order to increase the likelihood that the system can be implemented in a variety of settings, MSHIS was designed to be used with a variety of hardware and software configurations. *TECHNOLOGY OPTIONS* evaluated for data collection and management included the following:

- Personal computers, Macintosh equipment, video display terminals, mobile and hand-held computers;
- Optical Mark Reader (OMR) and optical character reader (OCR);
- FAX, Voice and Telephone Response Systems;
- Magnetic card technologies including magnetic strip cards and smart cards.

2. Software

Throughout the project, MSHIS staff served as a resource for information on software options. Some existing systems such as SPEDIS (New Hampshire Special Education Information System) and MIIS (Massachusetts Immunization Information System) were explored as potential models for the MSHIS. While the MSHIS project did not conduct a comprehensive evaluation of available software for computerized

health data systems, a basic tool for evaluating software was developed to aid schools in considering options.

MSHIS staff also developed a School Health Software Report which provided basic information about software and outlined product capabilities related to MSHIS requirements. Since the report was first distributed in June of 1994, a number of other software options have become available, and new or improved commercial products are being developed each year.

3. Technical Recommendations and Guidelines

General recommendations were developed to assist schools in planning and system design, data collection and system management, and to prevent risk of breaches of confidentiality and security.

a. MIS Design Recommendations

The Technology Team recommended that a school system's computerized Management Information System (MIS) include the following *FUNCTIONAL CAPABILITIES:*

- 1. Systems should integrate demographic, health status, health service and attendance data. Such a comprehensive database would facilitate the coordination of care across health service delivery sites including traditional health care settings. In addition, the relationship between school and health indicators could be explored.
- 2. The MIS should be capable of developing both standard and customized reports on the population served and should be capable of query, reporting, client intake and close-out at the local level.
- 3. The MIS should have the ability to transmit data from remote local sites to the host system. Data files should be transmitted to the host in acceptable electronic media (modem, disk).
- **4.** Systems should include built-in validity checks to assure data integrity.
- 5. Systems should have the capability to broadcast and receive messages across local school systems.
- 6. The capacity to share school health records electronically between schools within the same district when students change grades, and across school districts when students transfer, should be developed.

7. On-line help should be available.

b. UHDS Data Transmission Standard

A key feature of the MSHIS system is the transfer of UHDS Version 2.0 data from school districts to a central database. This database, the MSHIS Central Data Repository (CDR), will store the UHDS information for analysis and reporting in accordance with the goals of the MSHIS project. A technical document was developed to guide schools in preparing UHDS data for electronic submission to the Central Data Repository.

The *UHDS DATA TRANSMISSION GUIDELINES* consist of the following specifications:

- Each UHDS data submission is in the form of a single electronic file in DOS-text format.
- A school system participating in the MSHIS may make a single consolidated submission for the entire school district, or multiple submissions from separate schools.
- The individual-level data may be submitted in a single line of text once per year. (Note: Massachusetts does not collect individual-level data, only aggregate data.)
- File transfer as required under the MSHIS design can be accomplished in 4 ways, via:
 - floppy disk (PC-compatible).
 - direct serial port link.
 - modem connection.
 - network connection.
- The transmission of data is accompanied by the following identifying labels:
 - school district name and code.
 - year of submission.
- Name and phone number of contact person in case of problems or questions.

As previously noted, in the interest of maximizing opportunities for participation in the MSHIS, schools were permitted to submit data regardless of the hardware and software they were currently using. In addition, MSHIS staff developed a scannable form (used by pilot sites) that incorporated a core subset of the UHDS for schools whose information systems were not yet automated at the time of the pilot implementation.

III. Confidentiality, Privacy, and Data Security

CONFIDENTIALITY OF SCHOOL RECORDS

At the time the MSHIS was developed, the school record consisted of two components: transcripts, and a temporary record which included school health records and personal notes. The school health record is an instrument utilized by school systems to capture and record health data. As part of the "temporary school record," the content, uses of, and access to the school health record are regulated by law -- the Massachusetts Department of Education student record regulations (603 CMR 23.00: M.G.L. c. 71, 34D, 34F).

State and Federal regulations permit access to anonymous information from the student record by state officials, under certain circumstances and in accordance with guidelines specified in the Massachusetts Department of Education Regulations, without specific informed written consent of the student or parent. The confidentiality protection provided by these regulations is not as strong as that which is available for medical records. Because school records do not have the same confidentiality protection by law as medical records, maintaining confidentiality, privacy and data security for the UHDS data was a primary concern throughout the project.

During the development of the MSHIS, the Confidentiality of School Records Committee agreed that the highest level of security should apply, regardless of whether aggregate or individual data was collected during the pilot demonstration phase. To specify and standardize the confidentiality and security protection procedures the committee developed the *Confidentiality and Data Security Report*. This report gave specific guidelines for protecting data security based on the following guiding principles:

SECURITY GUIDING PRINCIPLES

- UHDS data, as part of the student health record, must be treated with the utmost professional care for the privacy of students and their families.
- Methods of securing student health data should include both physical security and computer security.
- Personally identifying data should be retained only at the local level.

One of the guiding principles for the development of the MSHIS states that "safeguards must be built into the system to protect confidentiality and right to privacy and address the requirements of freedom-of-information mandates." *The Confidentiality and Data Security Report* provides

standard definitions of terms, UHDS coding standards, and addresses security and confidentiality issues, backup procedures and data collection and submission procedures, so as to guarantee secure collection of anonymous, individual-level data. Although the decision was made to collect only aggregate data, the stringent guidelines contained in the *Confidentiality and Security Report* are expected to be useful in situations where individual-level data is collected elsewhere.

PERMANENT STUDENT IDENTIFICATION CODE

To protect confidentiality, the recommendation was made to include no personally identifying information (student name or address) when local schools send data to the Central Data Repository. However, one of the MSHIS objectives was to collect data in a way which maintains longitudinal accuracy. As a student's record accumulates over time at the central repository, the system must know that data applies to a single building, even if he/she has transferred to a different school or moved among school systems. Therefore, in order to reconcile the conflict between maintaining confidentiality and allowing for longitudinal data analysis, the following strategy was devised.

When a student's data first arrives anonymously at the central repository, a permanent unique identifier would be assigned to each new record and used each time data regarding that record is transmitted to the repository. To further guarantee confidentiality, identifiers such as social security numbers would not be used, but rather a Permanent Student ID code (PSID) that uniquely identifies one record throughout its life. It was determined that the PSID should consist of a 2-digit state number prefix, a four-digit school district number, and an eight-digit student identifier.

Under this system, each new record would be assigned a PSID upon entering school. The PSID would be included in the student's health record when he or she enters a new school. However, in Massachusetts, due to parental concerns regarding confidentiality, a permanent student identifier (PSID) was not assigned during the pilot phase of the project because only aggregate data were submitted to the central repository.

PILOT SITE SELECTION AND IMPLEMENTATION

After informal site visits were made to nine public school districts to gather preliminary information regarding school health services and resources, a request for applications to participate in the MSHIS was sent to all superintendents and nurse managers in the Commonwealth. The application requested a description of existing computer and/or technology systems, a characterization of the school system, and an explanation as to why the school district believed it would be a good pilot site. Forty-six applications were submitted to the MDPH, from which six school districts were chosen as pilot sites for the MSHIS.

In choosing sites for the pilot-testing phase of the project, MSHIS staff considered factors such as school district size, existing computer technology, geographic location, willingness to participate and the type of community the school district served. Particularly large school districts were excluded from the pilot-test in order to include more than one school district. Schools with a range of existing computer technology capability were included in the pilot-test. Since the two MSHIS project staff were located in Boston, it was not considered feasible to locate pilot sites outside of Massachusetts. School districts participating in the MSHIS included those located in suburban, rural and urban areas and schools in the western and eastern portions of the state.

A site-specific report was generated for each of the six pilot demonstration sites to summarize the experience of each site throughout the MSHIS project. Site reports included the following components:

SITE REPORT COMPONENTS

- Listing of local project team
- School district profile
- Planning process
- Information systems overview
- Paper-based systems overview(existing health-related forms)
- Implementation steps
- Design change and UHDS redefinition
- Data collection and reporting experience
- Evaluation

A comprehensive summary of the pilot-testing results across the six pilot sites was not deemed appropriate due to the uniqueness of the experience at each pilot site. However, the overall project evaluation section of this

report does reflect lessons learned from the pilot-testing in each case.

DATA COLLECTION, ANALYSIS, AND REPORTING

1. Collection of UHDS Data

Under the MSHIS, health-related information is recorded throughout the school year by school health professionals (school nurses) and by school administrative personnel using whatever systems are in place at the local school district. To the greatest extent possible, this information is categorized or coded in accordance with UHDS coding standards.

During the 1994-95 school year, MSHIS data was collected from the six pilot site districts throughout Massachusetts. Data collected from each of the pilot demonstration sites came predominately from the databases used by the school nurses and/or the overall administrative data system in use at each site. Each school system in the pilot had its own system for recording student health information. All pilot sites maintained this information on computer, either together or with other student records, or as a separate health information system. Data collection was delayed for seven months in order to fully prepare systems that guaranteed confidentiality protection.

The original idea of the MSHIS was that the local school or town/city health department/MIS professionals would cooperate to collect the UHDS data at the end of each school year and send the data file to the central repository either electronically or by mailing a diskette in accordance with the UHDS Data Transmission Standard. However, because of start-up difficulties, MSHIS staff ended up going to each pilot site to assist in the data collection process. In some cases, data was transcribed onto paper and in others, printouts were taken directly from the school's automated system.

2. Data Collection Issues

The problems associated with data collection are complex due to the diverse nature of school technological capabilities. Collection of data elements was dependent upon capabilities of the software being used, the resources for data entry, whether or not a supplemental scannable survey was conducted, the ease with which data could be collected, the local data support systems, and compatibility between definitions used by the local school district and the MSHIS UHDS. For these reasons, data collected at each demonstration site during the pilot-testing phase was not uniform across districts.

3. Data Analysis

While the long-range goal of MSHIS was to standardize the types of data collected, it was learned that for some UHDS items, data from one site can not be validly compared to another site. First, pilot sites varied in what UHDS data elements they were able to collect so that there was data missing for some data elements. The only data elements collected uniformly at all pilot sites were information on gender, race/ethnicity, date of birth, school building and grade. Second, data was sometimes collected through different methods across sites; e.g., through a parent survey, a scannable form, or by direct entry into a hand held computer. Finally, data elements were defined differently in existing local databases.

Since Massachusetts decided to collect aggregate data only, it was neither possible to create an epidemiological database nor to analyze relationships among different data elements. As a result, it will not be possible to conduct certain sub-analyses of the pilot data at the Central Repository and it will not be possible to track individuals over time. However, for those students who do not change school districts, cross-tabulations and tracking of individuals can be done locally.

After many unanticipated delays and difficulties in piloting the data collection process, the central dataset was constructed in early February of 1996. Because the project ended February 22, 1996, there was insufficient time to develop composite data tables across sites or perform a more comprehensive evaluation. Should additional resources be made available, such analyses will be conducted and incorporated into a revised report.

PILOT SITE EVALUATION

The pilot-testing phase of the MSHIS project included an evaluation component. Six criteria were established to evaluate each pilot site. The *PILOT SITE EVALUATION CRITERIA* included the following:

Data Completeness: Was the pilot site able to submit data on all eligible records?

Dataset Evaluation: Which items in the Uniform Health Dataset were the pilot site able to collect?

Data Quality: Was the data submitted coded consistently and properly?

Participation Levels: What was the level of effort required on the part of all participants?

Procedural Review: What were the problems that arose in collecting and submitting data and how were they resolved?

Overall Satisfaction and Ongoing Development: Did the pilot project enhance the ability of the local site to efficiently capture and make use of health information? Will the district be continuing with the components developed under the MSHIS project and/or adding additional components?

While each site was evaluated individually, due to time constraints, it was not possible to conduct an overall evaluation of the pilot sites. To summarize individual site evaluations is beyond the scope of this summary due to the uniqueness of each site's experience during the course of the project.

OVERVIEW

In order to develop and implement the MSHIS, it was necessary to consider and address technical issues, concerns about record confidentiality, privacy and data security, and to develop analysis and reporting options. The project was successful in creating a data collection tool, in providing technical support to schools, and in implementing pilot-site testing. While substantial methodological problems were encountered in data collection, data was collected from each of the six pilot sites in aggregate form.

SUCCESS IN ACHIEVEMENT OF OBJECTIVES

The MSHIS project successfully met the following three objectives:

Objective 1: Creating local commitment and interagency and interstate collaboration.

The project was successful in involving representatives from all six New England states and in promoting ongoing communication throughout the life of the project. The Region I Advisory Committee provided a forum for the discussion of many data-related initiatives. In addition to involving public health professionals and educators from the six New England states, the project was successful in identifying the concerns of parents, advocacy groups and representatives of participating schools for further policy development.

Objective 2: Developing a standardized set of data elements reflecting the health status of children and youth for use by local school districts.

The project successfully accomplished its product goal by developing and piloting a Uniform Health Dataset and establishing data collection and reporting options for use by local schools.

Objective 3: Establishing and implementing pilot sites.

The project included six demonstration sites. All six demonstration sites were successful in contributing to the knowledge base accumulated through the test period.

RECOMMENDATIONS FOR THE FUTURE

The following recommendations for the future implementation, enhancement, and expansion of the MSHIS are based upon program evaluation and consideration of the issues associated with project development and implementation:

PROJECT RECOMMENDATIONS FOR MASSACHUSETTS

- 1. Confidentiality and legal issues need to be explored in more depth and joint MDPH/MDOE state guidelines and/or regulations should be developed to provide local school districts with guidance. The Safeguards and Security Document issued in March of 1996 should be periodically reviewed and revised to reflect system development over time. The involvement of parents, students and advocacy groups related to issues of confidentiality should be increased.
- 2. The Uniform Health Dataset should be revisited to refine the ten core data areas for ongoing data collection. Continued development of the UHDS is critical with special emphasis on the development of four specific indicators for which current measures do not exist. These indicators include an educational achievement measure; a psycho-social health measure; a functional measure; and a disability index. Data should not be collected if there are no resources for analysis and reporting or if there is no specific plan for use of the data. Finalization of UHDS and transmission standards should be accomplished prior to expansion of the pilot site.
- 3. A carefully thought-out long-term implementation process should be identified and specified in detail. The next step in the long-term implementation process is to concisely define each test phase. At the end of MCHB-funded grant, prototype testing was completed. The alpha test of the system would involve integration of the MSHIS with existing systems at the local site. Expansion of the pilot demonstration sites should be carefully planned and coordinated with the school calendar year to ensure successful implementation.
- 4. Resources are required for developing, storing, and managing the MSHIS database: adequate computer capacity; a questions/help desk; assistance in processing of submissions and identifying errors or improper procedures; and assistance with analysis and reporting. A full-time staff person is required at the Central Repository to manage a hotline or help desk, and to conduct data analysis, interpretation and reporting.

- 5. Evaluation of the six data collection and analysis options should be conducted in light of issues raised by the Confidentiality of School Health Records Committee.
- **6.** The provision of technical assistance to school districts within Massachusetts should be continued.
- 7. The original six pilot sites should be fully evaluated prior to expansion of the system in additional districts.
- 8. The School Health Records Automation Survey designed in the summer of 1995 should be conducted statewide to estimate the feasibility of, cost and time-line for possible phased-in implementation of computerized local school health records and state-wide collection of priority statistics.
- 9. The future success of the project is dependent upon the continued participation and involvement of educators and school administrators as well as public health and school health professionals.

PROJECT RECOMMENDATIONS FOR MASSACHUSETTS AND OTHER STATES

- 1. Continued interdisciplinary involvement in fields of health and human services, education, and technology is essential to the development, implementation and enhancement of the MSHIS. A comprehensive approach that integrates programs that cut across traditional boundaries is necessary. The MSHIS project needs to be viewed in the context of current school data collection requirements and should be redefined to address an educational audience.
- 2. Data collection across local sites should use the same methodology, timing of data collection and definitions. The MSHIS system should be usable in schools with a variety of technological capabilities. However, while it is important to maintain system flexibility, it is also necessary to maintain uniform data collection, particularly for the core dataset. Except in very small school districts (less than 200 students) an automated system would be required for an information system.
- **3.** Families, advocacy groups, local school representatives, health care providers, universities, state agencies and other organizations

and citizens should be involved in further system development to assure broad-based community involvement in future planning, implementation and evaluation phases.

4. MSHIS is not a single system, therefore choice of system depends upon the characteristics of the school district. It is important that school districts have technical assistance. The use of additional technologies should be further investigated.

RECOMMENDATIONS FOR THE FEDERAL GOVERNMENT

- 1. Health and Human Services and the Department of Education should spearhead an initiative to work collaboratively to establish an effective data administration function at the federal level.
- **2.** Various levels of government need to work together to fund the necessary information technology infrastructure.
- **3.** Key contacts should be identified in each of the fifty states to assist with ongoing system development issues.

FEASIBILITY OF MSHIS

In evaluating the feasibility of the MSHIS, it is necessary to examine the issues associated with its development and implementation from the local, state and national perspective. As previously discussed, the MSHIS pilot was limited to Massachusetts. Since the role of the school nurse and the availability of comprehensive school health varies by state and by locality, prior to extending the pilot-test, states should be categorized in terms of models of school health currently available. In addition, costs and benefits of system expansion should be evaluated and the role of the school in the delivery of health and human services should be determined.

Based upon the experience accrued through the pilot demonstration phase of the MSHIS project, ten factors were identified that are critical to the success of the project at the local level. MSHIS project staff found that the degree to which each of the pilot sites was able to collect and report on data was directly related to each of the following ten factors:

FACTORS NECESSARY FOR SUCCESS AT THE LOCAL LEVEL

- Appropriate health office staffing.
- Motivation to automate health records.
- Hardware availability/type of hardware.
- Software availability/type of software.

- Well-planned database that facilitates efficient MIS maintenance.
- Data entry time/data entry services.
- Initial training of staff.
- Ongoing staff training.
- Local technical assistance and support.
- Relationship with district MIS director/knowledge of district-wide MIS implementation initiatives.
- Strong security measures to protect data and record identity.

Successful pilot-testing of the MSHIS in six different areas of Massachusetts support the feasibility of state-wide implementation. However, a survey to assess the feasibility and cost of statewide implementation was not conducted during the grant because of time limitations.

The MSHIS project, in its original design, is feasible as a national prototype provided qualified staff are available at the local, state and federal level to collect, analyze and report data; automated systems are in place at all levels; and policy issues around the use of and access to data are resolved.

CONCLUSIONS

At the end of three years, the MSHIS has been determined to be a feasible means of obtaining data related to child and adolescent health. One of the next steps in refining the MSHIS is to further identify and incorporate data elements relevant to the linkage between health and education and develop data collection tools for those measures that were not tested in the pilot phase. Specifically, mental health and psycho-social development are identified as critical areas for which data would be useful. The collection of behavioral health statistics under the aggregate-only design may be the only acceptable means of collecting this sensitive data.

For ongoing data collection beyond the pilot phase, the issue of standardizing data collection should be reconciled with the need to maintain flexibility to accommodate many different existing local systems. Additionally, confidentiality was a major issue during the project. An oversight commission should be convened that is comprised of representatives of all concerned constituencies to address confidentiality issues. Once these issues are considered and addressed, it may be possible to expand the concept into other schools.

VI. Available Supplemental Documentation

In the process of developing the MSHIS, a number of documents were created to provide guidance to schools and to articulate the objectives of the MSHIS. The following *SUPPLEMENTAL DOCUMENTATION* is available by request from the Massachusetts Department of Public Health:

- School Health Software Report (first issue dated 1993, second issue dated 1994).
- Software Evaluation Tool.
- UHDS Transmission Standard.
- Confidentiality and Data Security Report.
- Safeguards and Security Documentation.
- Supplemental Scannable Survey.
- UHDS Aggregate Data Version.

To obtain additional information on the MSHIS project and copies of these documents, please contact: Office of Statistics and Evaluation, Bureau of Family and Community Health, Massachusetts Department of Public Health, 250 Washington Street, 5th Floor, Boston MA 02108. Telephone: (617) 624-5536.

.

APPENDIX I

MSHIS Key Participants

Steering Committee

The Steering Committee grew out of an internal project team established by the Massachusetts Department of Public Health to monitor project development over the course of the grant.

Region I Advisory Committee

The Region I Advisory Committee was comprised of high-level staff from all six New England states and was used as a forum throughout the development of the prototype system. The Committee included public health, education, school health, and information system professionals. Many of the individuals who served on the Steering Committee continued their involvement on the Region I Committee.

Technical Committee

The Technical Committee consisted of technical staff from various state agencies and school districts. The Committee held several meetings over the course of seven months and played a critical role in the initial design of the MSHIS system and in the evaluation of technology for the collection and transfer of data which was available at the time the MSHIS project was conducted.

Confidentiality of School Health Records Committee

The Confidentiality of School Health Records Committee consisting of staff in MDPH and other state agencies and school districts was established to provide guidance regarding issues of confidentiality and data security.

APPENDIX II

UNIFORM HEALTH DATA SET VERSION 2.0

MODEL SCHOOL HEALTH INFORMATION SYSTEM

UNIFORM HEALTH DATA SET VERSION 2.0

Table of Contents by Field Name

Overview
Matrix Summary
Data Element Summary Listing
Data Element Detail

YearEntry 5	Sports 12
State 5	WorkPermit13
SchoolDistrict 5	WorkHours 13
Local PSID 5	Functional Measure 13
CheckDigit6	EducaMeasure 13
Gender 6	Disability Index 13
Date-of-Birth 6	PhysFitMeasure 14
Race/Ethnicity 6	PsychoSocMeasure. 15
YrSubmit 7	ScreeningCode 16
State 7	Problem17
SchoolDistrict 7	Referral 17
SchoolBldg7	Treatment
PSID 7	FollowUp 17
CheckDigit7	HealthInsur17
Date-of-birth 7	ExamCode 18
Grade 7	SourceOfCare 18
Height 8	VisitType 19
Weight 8	VisitNbr20
DateMeas 9	AssistDevCode 21
MaternEdu 9	CondCode 22
EnvironSmoke 10	MedsCode 26
MovedCount 10	MedsFreq 27
EmerContact 11	MedsAdmin28
DispositionCode 11	InjuryActivity 28
Section504 11	InjuryBodyPart 29
SPEDPrior 12	InjuryType29
SPEDReferral 12	TypeSchDist30
SPEDCurrent 12	KOC 30
DaysMissed12	TypeSchProg31
	NurseRatio 31
	NutritionBreak 31
	NutritionLunch 31

References

MSHIS Uniform Health Data Set

Field Name		Field Length	Field Format		Key:	<u>Key:</u>				
Sys	stem Entry of a New Stud	lent			X= 5	Submission	Required			
1. 2. 3. 4. 5. 6. 7.	YearEntry State SchoolDistrict Local PSID CheckDigit Gender Date-of-birth RaceEthnicity	4 2 3 8 1 1 8 1	numeric numeric numeric numeric numeric M/F MMDDYYYY see definition		W= Height/Weight V= Vision H= Hearing I= Immunization L= Lead Screening A= Anemia P= Postural Screen M=Measles Booster					
Sin	ngle Data Element Value	(End of Year Repor	ting)	K	2	4	7	10	12	
9. 10. 11. 12. 13. 14. 15.	YrSubmit State SchoolDistrict SchoolBldg PSID* CheckDigit Date-of-Birth	4 2 3 3 13 1 8	numeric numeric numeric numeric numeric numeric numeric MMDDYYYY	X	X	X	X	X	X	
16. 17. 18.	Grade Height Weight	2 6 5	numeric inches lbs.	X X X	X X X	X X X	X X X	X X X	X X X	
19. 20. 21. 22. 23.	DateMeas MaternEdu EnvironSmoke MovedCount	8 1 1 2	MMDDYYYY numeric Y/N/U numeric Y/N/U	X X X X X	X X X X	X X X X X	X X X X X	X X X X X	X X X X X	
24. 25. 26. 27.	EmerContact Dispositioncode Section504 SPEDPrior SPEDReferral	1 1 1 1	See definition Y/N/U Y/N/U Y/N/U	X X X X	X X X X	X X X X	X X X X	X X X X	X X X X	
28. 29. 30. 31. 32.	SPEDCurrent DaysMissed Sports WorkPermit WorkHours	1 3 1 1 2	Y/N/U numeric Y/N/U Y/N/U numeric	X X	X X X	X X X	X X X X	X X X X X	X X X X	
33. 34. 35. 36. 37. 38.	FunctionalMeasure EducaMeasure DisabilityIndex PhysFitMeasure PsychoSocMeasure UserDefined	2 2 2 2 2 2 2	numeric numeric numeric numeric numeric see definition	X X X X	X X X X X	X X X X X	X X X X X	X X X X X	X X X X X	

Multiple Data Element Values			K	2	4	7	10	12
			V					
39. ScreeningCode	1	see definition	I		V	V	V	
40. Problem	1	Y/N/U	H	V	V	H	Н	Н
41. Referral	1	Y/N/U	L	Н	H	P	P	
42. Treatment	1	Y/N/U	T		M	M		
43. FollowUp	1	Y/N/U	A					
44. Healthinsur	2	see definition	X	X	X	X	X	X
45. ExamCode	1	see definition	X	X	X	X	X	X
46. SourceOfCare	1	see definition	X	X	X	X	X	X
47. VisitsType	2	numeric	X	X	X	X	X	X
48. VisitNbr	3	numeric	X	X	X	X	X	X
49. AssistDevCode	2	see definition	X	X	X	X	X	X
50. CondCode	6	see definition	X	X	X	X	X	X
51. MedsCode	2	see definition	X	X	X	X	X	X
52. MedsFreq	1	see definition	X	X	X	X	X	X
53. MedsAdmin	1	see definition	X	X	X	X	X	X
54. InjuryActivity	2	see definition	X	X	X	X	X	X
InjuryBodyPart	2	see definition	X	X	X	X	X	X
56. InjuryType	2	see definition	X	X	X	X	X	X
57. UserDefined	2	see definition	X	X	X	X	X	X
District-Wide Data Element			K	2	4	7	10	12
58. TypeSchDist	1	numeric	X	X	X	X	X	X
59. KOC	1	numeric	X	X	X	X	X	X
60. TypeSchProg	3	numenc	X	X	X	X	X	X
61. NurseRatio	5	see definition	X	X	X	X	X	X
62. NutritionBreak	3	percentage	X	X	X	X	X	X
63. NutritionLunch	3	percentage	X	X	X	X	X	X

MODEL SCHOOL HEALTH INFORMATION SYSTEM

UNIFORM HEALTH DATA SET (UHDS)

Version 2.0 OVERVIEW

January 5, 1995

The data elements, definitions and clarification of issues, forming the foundation of Version 2.0 of the Uniform Health Data Set (UHDS), were gleaned from discussions of the Region I Advisory Committee, Massachusetts Steering Committee, state-specific meetings and interviews with professionals in the field of comprehensive school health both at the state and local level. UHDS data collection and annual reporting will be tested over the next six months. This document provides the code names, field lengths, definitions and points of data collection for all data elements in version 2.0 of the data set. Version 2.0 represents the pilot demonstration site test dataset.

Data elements are divided into four components:

- 1. System Entry Data Elements which are collected at the time of initial student registration into the system
- 2. Data elements which are comprised of a single value per student, per submission
- 3. Data elements which can be comprised of zero, one or multiple values per student per submission, and
- 4. District-wide data elements submitted annually.

The specific data elements included in the UHDS for which we currently do not have identified measures are as follows:

- 1. Functional Measure
- 2. Educational Measure
- 3. Disability Index
- 4. Psychosocial Measure

Measures for the above-cited elements and refinements to the dataset will be developed based on pilot site experience over the next six months and incorporated into UHDS Version 3.0. Various survey tools and instruments are being evaluated for implementation during pilot prototype testing.

MODEL SCHOOL HEALTH INFORMATION SYSTEM

UNIFORM HEALTH DATA SET (UHDS)

Version 2.0
DATA ELEMENT SUMMARY LISTING
January 5, 1995

SYSTEM ENTRY DATA ELEMENTS

Data elements 1 - 8 are collected only once, at the time that the child is initially assigned a

Permanent Student Identification Code (PSID).

1. YearEntry: The year in which the student enters the MSHIS database. For most

students, this will be at entry-into-Kindergarten.

2. State: The state that the school district is in at the time the child first

enters school and is initially assigned a PSID.

3. SchoolDistrict: The school district in which the child is initially enrolled.

4. Local PSID: The Permanent Student Identification Code (PSID). The PSID is

assigned once at the time the child enters the MSHIS and this ID

follows them throughout their school years.

5. CheckDigit: A check digit is included to verify PSID accuracy

6. Gender: Gender of the student
7. Date-of-Birth: The student's date-of-birth
8. Race/Ethnicity: Race/ethnicity of the student

SINGLE DATA ELEMENT VALUE (End-of-Year Reporting)

Each annual submission will include elements 9 - 57 for all students in grades K, 2, 4, 7, 10 and 12.

9. YrSubmit: The year during which the student data is submitted to the MSHIS

Central Repository

10. State: The state the school district is located in at the time of data

submission.

11. SchoolDistrict: The submitting school district

12. SchoolBldg: The school building within the district

13. PSID: The Permanent Student Identification Code (PSID). This is the

same ID code that the child was originally assigned when they

entered the system.

14. CheckDigit: A check digit is an additional digit computed from the rest of the

digits in the PSID according to a predetermined algorithm. The purpose of the check digit is to detect data submissions that contain

an error.

15. Date-of-birth: The student's date-of-birth. This is a redundant element collected

at each submission to verify the correct PSID.

16. Grade: The grade that child is in at the time of data submission

17. Height: Height of the student18. Weight: Weight of the student

19. DateMeas: Date on which height and weight measurements were taken.

20. MaternEdu: Maternal Education Level

21. EnvironSmoke: Environmental smoke in the home

22. MovedCount: The number of times the child moved either prior to entry-into

kindergarten or during the school year.

23. EmerContact: Is emergency contact information on file with the school.24. DispositionCode: Indicator of expected data submission for following year.

25. Section 504: Is the child Section 504 eligible?

26. SPEDPrior: Has the child received previous SPED services?

27. SPEDReferral: Was the child referred for a SPED Evaluation as a result of school

based screening?

28. SPEDCurrent: Is the child currently receiving SPED services?
29. DaysMissed: Annual Days of School Missed (attendance)

30. Sports: Does the child participate in competitive sports which require a

comprehensive physical examination

31. WorkPermit: Does the child currently have a work permit

32. WorkHours: On average, how many hours per week does the child work?

33. Functional Measure: Functional Assessment Measure (see definition section)

34. EducaMeasure: Developmental or Educational Achievement Measure (to be

developed based on school grade reports)

35. Disability Index: Disability Index (to be developed)

36. PhysFitMeasure: Health Related Physical Fitness Measure

37. PsychoSocMeasure: Psycho-social functioning measure (to be developed)

38. UserDefined: This field is intended as a place holder to be defined by the local

school district.

MULTIPLE DATA ELEMENT VALUES

Data elements 39 - 43 refer to specific screening codes such as vision and hearing testing, scoliosis screening, etc. Each screening code is tracked on four dimensions (40 - 43).

39. ScreeningCode: Codes for screening programs (see definition)

40. Problem: The screening has resulted in the need for a follow-up referral

(problem identification)

41. Referral: If a problem was identified, was a follow-up referral letter sent to

narents

42. Treatment: Was the child seen by a provider as a result of the referral

43. FollowUp: Required monitoring and follow-up on the part of the school nurse.

44. HealthInsur: Child's current health insurance status

45. ExamCode: Which physical and/or dental examinations has the child had? (see

definition)

46. SourceOfCare: Child's Use of various sources of health care (see definition)

47. VisitType: Type of visits to the school nurse (see definition)

48. VisitNbr: Number of visits to the school nurse

49. AssistDevCdistrict: Child's use of assistive devices (see definition) 50. CondCode: Existing health conditions (see definition)

51. MedsCode: Specific medications administered in school (see definition)

52. MedsFreq: Frequency with which medications are administered (see definition)

53. Meds Admin: Who is administering the medication (see definition)

54. InjuryActivity: The activity that the student was engaged in at the time of the

injury (see definition)

55.InjuryBodyPart: The specific part of the body that was injured (see definition)

56. Injury Type: The type of injury

57. UserDefined: This field is intended as a place holder to be defined by the local

school district

DISTRICT-WIDE DATA ELEMENTS

Elements 58 - 63 reflect district-wide aggregate data.

58. TypeSchDist: The type of school district (see definition)
59. KOC: The "Kind of Community" (see definition)

60. TypeSchProg: The type of school health programs by building (see definition)

61. NurseRatio: The nurse-to-student ratio by building (see definition)

62. NutritionBreak: The percentage of students in the school district that participate in

the free and/or reduced breakfast program (see definition)

63. NutritionLunch: The percentage of students in the school district that participate in

the free and/or reduced lunch program (see definition)

MODEL SCHOOL HEALTH INFORMATION SYSTEM

UNIFORM HEALTH DATA SET

Version 2.0

January 5, 1995 SPECIFIC DATA ELEMENT DETAIL, CODE DEFINITIONS AND CLARIFICATION OF MEASUREMENT ISSUES

Data element and code definitions are included in this document. When applicable, data collection justifications include citations from the following sources:

- 1. Healthy People 2000 Objectives and Identified Research Areas
- 2. Title V of the Social Security Act, Maternal and Child Health (MCH) federal reporting requirements
- 3. Section 504 of the Rehabilitation Act of 1973
- 4. Massachusetts* State Mandated Health Screenings and Immunizations
- 5. Data collected under the Massachusetts* Mandated School Health Record
- 6. Massachusetts* Department of Education Chapter 188 and 766 Requirements
- 7. Massachusetts* Tobacco Control Program

The MSHIS UHDS is designed to be flexible to accommodate variations among states regarding mandated screenings and immunizations.

Data elements 1-8 are collected only once, at the time that the child is initially assigned a Permanent Student Identification Code (PSID)

1 <u>. </u>	YearEntry	Year of Entry into the MSHIS
		Length of Field = 4 Format = numeric
		For prototype testing, the code should always be 1995
2	State:	State within which the school district is located Length of Field = 2 Format = numeric
		C
		For prototype testing Massachusetts = 01
3	SchoolDistrict:	The school district in which the child is initially enrolled.
		Code numbers are assigned to each school district in Massachusetts by the
		State Department of Education.
4	Local PSID:	The Permanent Student Identification Code
		Length of Field = 13 Format = numeric

The PSID is a code that uniquely identifies one individual student throughout their school-age years. A PSID must be assigned to each student and used each time health data is transmitted to the central data repository. When assigning a new PSID, the school district will use as a prefix a

two-digit state number and a three-digit school district number supplied by the state or regional central authority. The remainder of the PSID will be an arbitrary 8-digit number, to be assigned uniquely by the school district. For more detailed information on the PSID see the **Confidentiality and Data Security Report.** The correspondence between the PSID and the student must be kept confidential and should be handled in the same manner as all confidential student record information.

PSID's should be assigned sequentially. For example:

State District Unique local # 01 123 12345678

In the example, the PSID would be: 0112312345678

5. CheckDigit: A validity check on the accuracy of the PSID

Length of Field = 1 Format = numeric

To ensure accuracy of data, a check digit is added to the PSID to detect data submissions that contain an error. The check digit is an additional digit computed from the rest of the digits in the PSID according to a predetermined algorithm. For initial prototype testing adding up the other digits and taking the right-most digit of the sum will be used. When processing the submitted information, the central data repository will reject any data with an incorrect PSID check digit. Using the example above, the check digit would equal the right-most digit of the sum of all 13 numbers included in the PSID. The sum = 43 and the right most digit = 3.

6. Gender: Gender of the student.

Length of Field = 1 Format: M = Male

F = Female

7. <u>Date-of-Birth:</u> The student's date-of-birth

Length of Field = 8 Format: numeric

MMDDYYYY

M = 2 digit month

D = 2 digit day

Y = 4 digit year

For example: Month = September = 09

Day = 10 Year = 1981

Date-of-birth = 06101981

8. Race/Ethnicity: Race/ethnicity of the Student

Length of Field = 1 Format: numeric

To ensure consistency of data collection during prototype testing, the codes used for this data element are identical to the codes used in the School-Based Health Center Data System. It is recognized that these codes are inadequate and they are currently under review, however, for prototype testing the codes used for race/ethnicity are as follows:

- 1 = White, non-Hispanic
- 2 = Black, non-Hispanic
- 3 = Hispanic
- 4 = Asian/Pacific Islander
- 5 = American Indian
- 6 = Other

EACH ANNUAL SUBMISSION WILL INCLUDE ELEMENTS 9 - 57 FOR ALL STUDENTS IN GRADES K, 2, 4, 7, 10 AND 12

9. <u>YrSubmit:</u> <u>Calendar Year of data submission</u> Length of Field = 4 Format: numeric

The year during which the student data is submitted to the MSHIS Central Repository by the school district. For prototype testing the 1994 - 1995 year submission would be coded 1995.

10. State: The state the school district is located in at the time of transfer.

For prototype testing, use the same coding as data element # 2: State

11. SchoolDistrict: The submitting school district

The same codes are to be used as defined in data element #3

- 12. SchoolBldg: The school building within the district
- 13. Permanent Student Identification Code: See data element # 4 for brief description
- 14. <u>CheckDigit:</u> See data element # 5 for brief description
- 15. Date-of-Birth: The students date-of-birth

This is a redundant element collected at each submission to verify the correct PSID.

16. Grade: The grade that the child is in at the time the data is submitted.

Length of Field = 2 Format: numeric

For example: If the student is in grade 4, this element should be coded 04. Kindergarten should he coded as 00.

Height and weight measurement techniques were recommended by the Massachusetts Department of Public Health Nutrition Education Task Force. 17. <u>Height: Height of the Student</u>
Length of Field = 6 Format: numeric

The individual students' height is measured in inches to the nearest eighth inch. Measurement should be recorded in decimal format with 2 digits to the left and 3 digits to the right of the decimal point. For example: 45.125

The physical growth of school-age children is an important indicator of nutritional status. Applying precise measurement techniques and using appropriate measuring equipment is essential to assure accuracy.

To be useful, **measurements should** not only be accurate but also recorded and plotted on a standardized National Center for Health Statistics (NCHS) gender-specific growth chart. Height and weight is plotted against age and compared with standardized percentiles (5th and 95th) as well as previous measurements. It is important to weigh and measure on a regular basis and plot the information so that the child's growth pattern can be clearly represented and children at risk who may need referral for further assessment can be identified.

Appropriate technique for measuring height is as follows: Choose a non-stretchable tape attached to a vertical, flat surface such as a wall. The measuring apparatus attached to spring balance scales is <u>not</u> appropriate equipment for measuring height. A right angle head board is needed to take the measurement. In addition, utilizing appropriate technique includes positioning the child correctly against the measuring tape. Have the child remove all but minimal clothing including removal of shoes and anything worn on the head. It is also recommended to have one person responsible for taking heights as measurements taken by different individuals may vary. Position the child so that the shoulder blades, buttocks and heels are touching the wall or vertical surface of the measuring device. The feet must be flat on the floor, slightly apart, legs and back straight and arms at sides. The head is usually not in contact with the measuring surface. Lower the moveable headboard until it firmly touches the crown of the head. Read the measurement to the nearest 1/8th inch. Repeat the adjustment of the headboard and re-measure until two readings agree within 1/8 inch.

- * M.G.L. c.71, s.57 (and related regulations 105 CMR 200.000 200.920) Annual measure of height.
- * Included on Massachusetts School Health Record

18. Weight: Weight of the Student

Length of Field = 5 Format: numeric

The individual students' weight is measured in pounds to the nearest half pound. Measurement should be recorded in decimal format with 3 digits to the left and 1 digit to the right of the decimal point. For example: 105.5

* Healthy Children 2000 Objective: Reduce overweight to a prevalence of no more than 15 percent among adolescents aged 12 - 19.

- * M.G.L. c.71, s.57 (and related regulations 105 CMR 200.000 200.920) Annual measure of weight.
- * Included on Massachusetts School Health Record

19. <u>Date Meas:</u> Date on which height and weight measures were taken Use same format as data element # 7: Date-of-Birth

In order to compute the nutritional measures identified as being important, it is necessary to collect not only the height and weight of the individual student and their date-of-birth but also the date on which the height/weight measurements were taken. This will allow for the calculation of such measures as;

- (l) Short stature (low height-for-age defined as less than the 5th percentile);
- (2) Underweight (low weight-for-height defined as less than the 5th percentile); and,
- (3) Overweight (high weight-for-height defined as greater than the 95th percentile)

In addition to the above, a child should be referred if their growth pattern changes dramatically. For example, a child consistently at the 50th percentile, drops to the 10th percentile.

- * Proportion of children who have attained appropriate weight-for-height is a Title V MCH data element.
- * Included on Massachusetts School Health Record

20. <u>MaternEdu:</u> <u>Maternal Education: Highest grade completed</u> Length of Field = 1, Format: Numeric

The following categories will be used to denote the maternal education level

College graduate or more Some college post High School High School Graduate or received GED Less than High School Unknown

Justification:

The association between socioeconomic status (SES) and disparities in childhood health and mortality has been well-documented. Family income has been found to predict differential prevalence of ear disease, hearing loss, visual problems, low birthweight, meningitis, rheumatic fever, iron deficiency anemia, and elevated lead levels. References are included at the end of the UHDS document. While household income is a very powerful determinant of child health status, and is thus an important variable to collect, it is not always feasible to obtain. Given the sensitive nature of income information, maternal education level was recommended as a proxy indicator of SES.

In the U.S., race and socioeconomic status are highly associated. However, while researchers almost always obtain race information, not all collect data on more proximal indicators of SES such as education level or employment status. When differences by race are found with no SES information to elucidate the effect, misinterpretation of the findings could occur helping to propagate racial stereotypes. Haan & Kaplan (1985) determined that, after adjusting for SES differences, racial differentials in health decreased significantly. Boback et al (1994) noted that mother's education was the only significant SES predictor of a child's height, after taking into account parental height and birthweight. Mare (1982) found that rates of child mortality differed by maternal education regardless of race. While data on paternal education is helpful, maternal education is more widely collected because children are more likely to live with a single mother than a single father. The advantage of maternal education over maternal employment data is that employment tends to be more variable over time than education. Additional references are provided at the end of the UHDS document.

21. <u>EnvironSmoke</u>: <u>Does anyone in the home currently smoke cigarettes</u>

Length of Field = 1 Format: Y = Yes N = NoU = Unknown

This data element was included to provide a measure of the effectiveness of tobacco control programs to reduce environmental tobacco smoke in the home.

- * Healthy Children 2000 Objective: Reduce to no more than 20 percent the proportion of children aged 6 and younger who are regularly exposed to tobacco smoke in the home (related objective).
- * Massachusetts Tobacco Control Program Objective: Decrease the percent of children exposed to ETS at home.

22. <u>MovedCount:</u> The number of times the child moved Length of Field = 2, Format: Numeric

The mobility of the student population was identified by school health professionals at the local level as representing a significant problem: both in terms of its impact on learning, the provision of quality health services and in terms of health records management.

Example: If the student moved 5 times during their Kindergarten Year, this data element should be coded 05. The move is counted even if it does not result in a change of school assignment.

23. EmerContact: Availability of Emergency Contact Information

Length of Field = 1 Format: Y = Yes N = NoU = Unknown

Is emergency contact information on file with the school? It is recognized that there can be many reasons why emergency contact information is not on file, however, this element is a gross measure of risk. An address is sufficient to indicate emergency contact information on file as some families do not have telephones. It is recognized that some schools are more aggressive in collecting emergency contact information, and that this element may be measuring the success with which schools are collecting this data, however, the data was still felt to be of use as a gross measure of risk.

24. <u>DispositionCode: Indicator of expected data submission for following year</u> The purpose of this code is to identify children for which data is not expected to be collected in the future.

0 = Continuing

1 = Graduation from H.S.

2 = Death

3 = Transferred to a different school

4 = Dropout

5 = Other

25. Section 504: Is the child 504 eligible?

Length of Field = 1 Format: Y = Yes

N = No

U = Unknown

As part of the Rehabilitation Act of 1973 (PL 93-112) Congress enacted section 504, which provides that "no otherwise qualified handicapped individual in the U.S., shall, solely by reason of his handicap, be excluded from the participation in, be denied the benefits of, or be subjected to discrimination under any program or activity receiving Federal financial assistance." The regulation is divided into seven sub-parts. Subpart D is concerned with elementary and secondary education. The regulation sets forth evaluation requirements designed to ensure the proper classification and placement of handicapped children. The feasibility of including Section 504 compliance assurance reporting in the MSHIS data base will be investigated. Accurate data on 504 students is necessary in order to ensure that all aspects of the regulations are followed. The majority of students that are potentially eligible or eligible under 504 can be found on the nurses chronic health care logs. This will assist school systems in fulfilling the requirements of Section 504.

* Section 504 of the Rehabilitation Act of 1973, 29 U.S.C. 706, with regard to federal financial assistance administered by the Department of Health,

Education and Welfare. Subpart D applies to preschool, elementary, secondary and adult education programs.

Special Education Services

* Massachusetts Department of Education Chapter 766 Kindergarten entry screening requirements include the existence of the possible need for special education and the history of placement in special education programs.

26. SPEDPrior: Has the student previously received special education services?

Length of Field = 1, Format: Y = Yes

N = No

U = Unknown

27. SPEDReferral: Has the student been referred by school personnel for a special

education evaluation?

Length of Field = 1 Format: Y = Yes

N = No

U = Unknown

28. SPEDCurrent: Is the student currently receiving special education services?

Length of Field = 1 Format: Y = Yes

N = No

U = Unknown

29. <u>DaysMissed</u>: Annual days of school missed

Length of Field = 3 Format: Numeric

This data element will be collected through the centralized attendance system used at each of the schools in question. For example: If a student missed 15 days of school during Kindergarten this data element would be coded 015.

30. Sports: Does the child participate in school-based competitive sports?

Length of Field = 1 Format: Y = Yes

N = No

U = Unknown

This element, in conjunction with the ExamCode element, measures compliance with the mandate that students receive a physical exam before participating in school-based, competitive sports. It is recognized that there are instances where a student is issued a work permit, however, the student is not working.

* Annual physical examination of school children is required before participation in competitive sports.

Work Permits

Children under 16 and over 14 years of age require work permits. A physical examination is required prior to the issuance of a work permit. The permit is issued by the Superintendent or his/her designee and requires a thorough physical examination.

- * Work permits are required for children under 16 and over 14 under Massachusetts Child Labor Law
- 31. WorkPermit: Does the child have a work permit

Length of Field = 1 Format: Y = Yes

N = No

U = Unknown

32. WorkHours: How many hours per week does the child work on average

Length of Field = 2 Format: Numeric

33. Functional: Functional Assessment Measure: Currently undefined

"Functional severity is the impact of the disorder on an individual's ability to perform age-appropriate activities, irrespective of illness type and under a broad range of circumstances. Both physiological and psychological factors may mediate functioning. People with equal physiological or morphological disorders may vary widely in the dysfunction or impairment they experience. Functional severity reflects the effect of a condition on a final common pathway - ability to conduct daily life" (Stein et al, p.3).

A functional measure needs to be developed which can be used in conjunction with the condition-specific listing or categorical approach (ConditionCode element 48). Various dimensions are discussed in the literature which attempt to describe a condition from a functional standpoint.

34. <u>EducaMeasure: Developmental or Educational Achievement Measure</u>: Currently undefined

A developmental or educational achievement measure will be developed based upon the school grade reports which vary from district to district. It is anticipated that a time limited task force will be convened to address the development of this measure.

35. DisabilityIndex: Disability Index: Currently undefined

There are two major conceptual frameworks in the field of disability: The International Classification of Impairments, Disabilities and Handicaps (ICIDH) and the "functional limitation" framework, which is not accompanied by a classification system. Both frameworks have four basic concepts:

<u>ICIDH:</u> Disease, Impairment, Disability and Handicap <u>Functional:</u> Pathology, Impairment, Functional Limitation and Disability

According to the Institute of Medicine (IOM), "until there is a consistently applied, widely accepted definition of disability and related concepts, the focus for preventive action and rehabilitation remain uncertain" (p. 20). "Current surveillance systems are condition specific, permitting identification of the risk factors associated with injuries. None of them, however, track the risk factors associated with the progression from pathology to impairment to functional limitation to disability" (p.21). The IOM Report further recommends that "a disability index, comparable to the infant mortality rate and the mortality and morbidity rates for cancer, heart disease and stroke, could serve as an important indicator of societal well-being and help focus the attention of the public and policymakers on this major public health problem" (p.23).

Both developmental disabilities, which include a group of conditions that begin during childhood, and injury-related disability, which affects primarily adolescents and young adults and disability associated with chronic disease should be incorporated into this index.

* Healthy Children 2000 Identified Research Needs: The epidemiology of disabilities - the distribution of disabilities within the population, especially groups with disproportionately high or low prevalence and risk factors for limitations in human activity.

36. <u>PhysFitMeasure: Health Related Physical Fitness Measure</u>: Currently undefined

In an effort to accomplish stated national objectives related to <u>Healthy People 2000</u>, various organizations have developed tests to estimate current status on the various defined components of physical fitness. The most common tests in the United States include:

- a. The Prudential Fitnessgram
- b. Physical Best
- c. The Presidents Challenge
- d. The Amateur Athletic Union Test and:
- e. Fit Youth Today.

Although these measures exist, a system for integrating them into a standard score is necessary. Health-related physical fitness is defined as the dimension of physical fitness that is associated with health status. Five components make up health-related physical fitness:

<u>Aerobic Capacity:</u> The physiologic capacity of an individual to take up and utilize oxygen to process metabolic fuels during exercise. Closely related to cardio-respiratory endurance. Synonyms are maximal oxygen uptake and maximal aerobic power.

Muscular Endurance: A health and performance related component of physical

fitness relating to the ability of muscle groups to exert a submaximal external force for a series of repetitious or successive exertions.

<u>Muscular Strength:</u> A health and performance related component of physical fitness relating to the maximal amount of external force that a muscle or set of muscles can exert.

<u>Body Composition:</u> A health-related component of physical fitness relating to the relative amounts of muscle, fat, bone and other vital parts of the body.

* Healthy Children 2000 Identified Research Needs: The relationship of total body fat and body fat distribution to health outcomes

<u>Flexibility:</u> A health-related and skill-related component of physical fitness relating to the range of motion available at a particular joint or set of joints.

- * Healthy Children 2000 Objective: Increase to at least 40 percent the proportion of people aged 6 and older who regularly perform physical activities that enhance and maintain muscular strength, muscular endurance, and flexibility.
- * Healthy Children 2000 Identified Research Needs: Research is needed, especially for population subgroups, to further define the relationships between physical activity, physical fitness, and
 - a. the incidence of cardiovascular disease
 - b. the incidence of obesity and selected types of body fat patterns
 - c. nutritional patterns
 - d. the adoption of healthy behavior patterns
 - e. the prevention and cessation of cigarette smoking
 - f. the treatment of alcohol and drug abuse
 - g. the incidence of depressive episodes among depressed people
 - h. improved mental well-being
 - i. quality of life

37. PsychoSocMeasure: Psycho-social functioning measure: Currently Undefined

Various tools exist to measure psycho-social functioning. One screening tool that might be considered as a measure for psychosocial dysfunction upon entry-into-Kindergarten is the use of the Pediatric Symptom Checklist (PSC). The checklist is completed by parents (takes 5 minutes to complete) and is specifically designed to screen school-aged children for psychosocial dysfunction. Scoring indicates normal range and children in need for further pediatric and/or psychological evaluation. The Child Health and Illness Profile (CHIP-AE) is another instrument under consideration. The DSM-IV "stress factor" will be researched as a potentially appropriate measure.

38. UserDefined: Measure to be defined by local district: Currently Undefined

This field is intended as a place holder to be defined by the local school district. It can be any measure that the district is interested in collecting and analyzing.

Elements 39 - 43 refer to specific screening codes. Each screening code is tracked on four dimensions (40 - 43).

39. Screening Code: Codes for screening programs

The following screening codes refer to data elements 32-35.

W = Height/weight

V = Vision

H = Hearing

I = Immunization

L = Lead Testing

A = Anemia

P = Postural Screen

M = Measles Booster

- * M.G.L. c.71, s.57 (and related regulations 105 CMR 200.000 200.920) require vision and hearing screening annually and annual postural screening in grades five through nine.
- * M.G.L. C.76, S.15 and 15c (and related amendments and regulations 105 CMR 220.000 TO 220.500) defines immunization requirements for entry into school. A measles booster for entry into seventh grade is also required.
- * M.G.L. c.lll, s.190 199A (and related regulations 150 CMR 460.050 and .060) require that children present evidence of having been previously screened for lead poisoning as a condition for entry into kindergarten.
- * Healthy Children 2000 Objective: Reduce significant hearing impairment to a prevalence of no more than 82 per 1,000 people.
- * Healthy Children 2000 Objective: Reduce the average age at which children with significant hearing impairment are identified to no more than 12 months.
- * Healthy Children 2000 Objective: Reduce significant visual impairment to a prevalence of no more than 30 per 1,000 people.
- * Healthy Children 2000 Objective: Increase to at least 80 percent the proportion of providers of primary care for children who routinely refer or screen children for impairments of vision, hearing, speech and language and assess other developmental milestones as part of well-child care.
- * Healthy Children 2000 Objective: Reduce indigenous cases of vaccine preventable diseases (Diphtheria, tetanus, polio, measles, rubella, congenital

- rubella syndrome, mumps and pertussis).
- * Healthy Children 2000 Objective: Increase immunization levels (basic immunization levels for school-aged children to at least 95 percent.
- * Required by Massachusetts School Health Record
- 40. Problem: The screening has resulted in the need for a follow-up referral

(problem identification)

Length of Field = 1 Format: Y = Yes

N = No

U = Unknown

41. Referral: If a problem was identified, was a follow-up referral letter sent to parents

Length of Field = 1 Format: Y = Yes

N = No

U = Unknown

42. Treatment: Was the child seen by a provider as a result of the referral

Length of Field = 1 Format

Y = YesN = No

U = Unknown

43. Follow-up: Required monitoring and follow-up

Length of Field = 1 Format Y = Yes

N = No

U = Unknown

44. HealthInsur: Child's current health insurance status

Length of Field = 2 Format: see codes below

The following codes are to be used:

01 = None

02 = Medicaid/MassHealth

03 = HMO Medicaid/MassHealth

04 = Kaleigh Mulligan

05 = CommonHealth

06 = Other Government (Champus)

07 = Blue Cross/Blue Shield

08 = HMO Blue - Medical West

09 = HMO Blue - Medical East

10 = Harvard Comm. Health Plan

11 = Bay State

12 = Tufts

13 = Pilgrim

14 = Fallon

15 = Kaiser

- 16 = State Hancock Plan
- 17 = Neighborhood Health Plan
- 18 = Central MA Health Plan
- 19 = United Health
- 20 = Health New England
- 21 = US Health
- 22 = Other HMO/PPO
- 23 = Commercial Insurer
- 24 = Other
- 25 = Unknown
- 26 = Dental Insurance

These codes are used in the Early Intervention Registration sociodemographic database. Include all that apply.

- * Healthy Children 2000 Identified Research Needs: Characteristics of populations lacking dental insurance
- 45. ExamCode: Has the child had an annual physical and/or dental examination?
 - K = Kindergarten Entry Physical Exam
 - R = Had a Physical Examination within 4 years
 - S = Sports Physical Examination
 - E = Special Education Physical Examination
 - W = Work Permit Physical Examination
 - D = Dental Examination
 - * M.G.L. c.71, s.57 (and related regulations 105 CMR 200.000 200.920) require physical examination of school children within six months prior to entrance into public schools or during the first year after entrance and at intervals of either three or four years thereafter. In addition, an annual physical exam is required before participation in competitive sports. Exams are also required for: (a) 14-16 year old youths requesting work permits; (b) any child in a private school when requested by parents; (c) any child when requested by a teacher in consultation with a school nurse.
- 46. SourceOfCare: Child's Use of Various Sources of health care

 Length of Field = 7 Format: see codes below

 Check all that apply

This information is collected at school registration or through interval health histories.

- 1 = Private Physician
- 2 = HMO Clinic
- 3 = Community Health Center
- 4 = School-based Health Center

5 = Hospital clinic

6 = Hospital Emergency Room

7 = Other

For example: a given student could have visited their private physician and attended the school-based health center as well as used the hospital emergency room. The code would be 0000146. All codes that apply should be reported.

* Healthy Children 2000: Increase to at least 95 percent the proportion of people who have a specific source of ongoing primary care for coordination of their preventive and episodic health care.

47. <u>VisitType:</u> Nature of the visits to the school nurse
Length of Field = 2 Format: Numeric see codes below

The visit type (e.g., first aid/injury or emergency) was combined with ranges of time spent in the school nurses office. This was done to "simulate" CPT-type coding used for third party billing purposes. This is critical to determine the contribution of school health programs to the overall primary care delivery system and to quantify the need for school/provider partnerships which maximize responsive service.

The following codes are to be used when entering data concerning the nature of the visit to the school nurse:

01 = First Aid/Injury less than 10 minutes

02 = First Aid/Injury 11 - 20 minutes

03 = First Aid/Injury 21 - 30 minutes

04 = First Aid/Injury 31 - 45 minutes

05 = First Aid/Injury 46 - 60 minutes

06 = Illness less than 10 minutes

07 = Illness 11 - 20 minutes

08 = Illness 21 - 30 minutes

09 = Illness 31 - 45 minutes

10 = Illness 46 - 60 minutes

11 = Medication less than 10 minutes

12 = Medication 11 - 20 minutes.

13 = Medication 21 - 30 minutes

14 = Medication 31 - 45 minutes

15 = Medication 46 - 60 minutes

16 = Mental Health/Counseling 15 minutes

17 = Mental Health/Counseling 30 minutes

- 18 = Mental Health/Counseling 45 minutes
- 19 = Mental Health/Counseling 60 minutes
- 20 = Emergency less than 10 minutes
- 21 = Emergency 11 20 minutes
- 22 = Emergency 21 30 minutes
- 23 = Emergency 31 45 minutes
- 24 = Emergency 46 60 minutes
- 25 = PPD (Tuberculosis)
- 26 = DPT/DT/dT (Diptheria/Pertussis/Tetanus)
- 27 = OPV (Oral Polio Vaccine)
- 28 = MMR (Measles/Mumps/Rubella)
- 29 = HiB (Influenza)
- 30 = HB (Hepatitis B)
- 31 = Flu Vaccine

Consultation always implies the provision of direct face-to-face interventions

- 32 = Student and/or Parent Consultation 15 minutes
- 33 = Student and/or Parent Consultation 30 minutes
- 34 = Student and/or Parent Consultation 45 minutes
- 35 = Student and/or Parent Consultation 60 minutes
- 36 = Student and/or Parent Telephone Consultation 37 = Student and/or Parent Telephone Message
- 38 =Special procedures
- 39 = Other

State mandated screenings (vision, hearing, lead screening, scoliosis, anemia) are tracked through elements 38 - 42 and are not included here.

48. <u>VisitNbr: Number of Visits to the school nurse</u>

Length of Field = 3 Format: Numeric

For example: A given student may have the following profile

018 visits for first/aid injury less than 10 minutes

001 visit for first/aid injury 31 -45 minutes

010 visits for medication less than 10 minutes

001 visit for emergency 11 - 20 minutes

The number of visits by type will be entered into the database.

49. AssistDevCode: Child's use of assistive devices

The following assistive device listing is part of the Project School Care Patient Data Base Record. The only exception is that eyeglasses were added to the listing.

Mobility

01 = Walker/Cane	05 = Prosthetics
02 = Wheelchair	06 = Crutches
03 = Prone Stander	07 = Hoyer Lift

04 = Safety Travel Chair

Respiratory Tract (breathing)

08 = Ventilator	11 = Tracheostomy (No Vent)
-----------------	-----------------------------

09 = Supplemental Oxygen 12 = Passy-Muir Valve

10 = Ventilator at night only

G I Tract (Nutrition)

13 = Gastrostomy Button	17 = Gastrostomy Tube
14 = Jejunostomy Button	18 = Jejunostomy Tube
15 = Peg	19 = Nasogastric Tube

16 = Parenteral Feeding

Elimination

20 = Colostomy $23 = Ilec$

21 = Ureterostomy 24 = Clean Int Catheter

22 = Continuous Catheter

Central Nervous System

25 = Helmet

Musculoskeletal

26 = Brace	27 = Ilizarov Frame

Communication

28 = Hearing Aide	31 = Talking device
29 = Computer	32 = Sip and Puff
20 - Evoglossos	

30 = Eyeglasses

50. <u>CondCode</u>: <u>Existing Conditions</u>

Length of Field = 9 Format = numeric see codes

The following list of health conditions was developed by carefully reviewing the Children's Hospital Project School Care Patient Data Base Record Diagnostic and Descriptive Codes and selecting a sub-set of the codes that are relevant to school-age children. Additional conditions were selected from two commercial school health software products used at two of the pilot

demonstration sites: School HealthCare ONLINE™ and HealthMaster. The length of the field is nine digits in that final coding will be in ICD-9 format.

Major system categories were developed by collapsing the categories used by Project School Care and the School HealthCare ONLINETM Software Package. Bolded type highlights those conditions which were either listed in both categorizations and/or which were included in School HealthCare ONLINETM, but not included in the Project School Care listing. Highly sensitive conditions (e.g., HIV, AIDS, psychiatric diagnoses, etc.) were omitted for the purposes of initial prototype testing. The appropriateness of including such conditions in the UHDS will be investigated as part of pilot testing. In addition, school nursing supervisors from three of the pilot demonstration sites reviewed the listing and those conditions they had never encountered during their careers were dropped from the list. This listing of conditions is being used for pilot testing starting in January 1995. Accurate ICD-9 classification system codes for each condition will be identified and linked to each condition in an attempt to standardize the data set.

- * Title V MCHB Reporting: The number of children with chronic illness and the type of illness.
- * Healthy Children 2000 Objective: Reduce to less than 10 percent the prevalence of mental disorders among children and adolescents (e.g., autism, attention deficit and hyperactivity, severe conduct disorders, depression and alcohol and other drug abuse).
- * Healthy Children 2000 Objectives: Increase to at least 75% the proportion of providers of primary care (school health service providers) for children who include assessment of cognitive, emotional and parent-child functioning, with appropriate counseling, referral and follow-up, in their clinical practices.
- * Healthy Children 2000 Objectives: Reduce the prevalence of serious mental retardation in school-aged children to no more than 2 per 1,000 children.
- * Healthy Children 2000 Objectives: Reduce diabetes to an incidence of no more than 2.5 per 1,000 people and a prevalence of no more than 25 per 1,000 people.
 - * Healthy Children 2000 Identified Research Needs: Research on the role of specific dietary factors in the etiology and prevention of chronic diseases including cancer, osteoporosis and stroke (preliminary discussions have been held with food service directors at two of the local school districts to discuss the possibility of including dietary measures in the UHDS)
 - * Healthy Children 2000 Identified Research Needs: The effects of nutrition on age-related impairment or organ system functions (cardiovascular, gastrointestinal/oral cavity, immune, musculoskeletal and nervous systems).
 - * Healthy Children 2000 Identified Research Needs: The barriers to prevention and early identification of cognitive, emotional and behavioral disorders, including social stigma associated with use of mental health services and care.

CENTRAL NERVOUS SYSTEM

OO1 Attention deficit Hyperactivity Disorder (ADHD)

- 002 Attention Deficit Disorder (ADD)
- 003 Cerebral Palsy
- OO4 Seizure Disorder (e.g., epilepsy, general, focal, etc.)
- 005 Mild Mental Retardation
- 006 Moderate Mental Retardation
- 007 Severe Mental Retardation
- 008 Profound Mental Retardation
- 009 Mental Retardation, Severity Unknown
- 010 Other Neurological Disorder
- O11 Specific Reading Disorder
- 012 Speech/Language Delay
- 013 Meningitis
- 014 Encephalitis
- 015 Encephalopathy
- 016 Microcephaly
- 017 Hydrocephalus
- 018 Head Injury
- 019 Spinal Cord Injury
- 020 Muscular Dystrophy
- O21 Spina Bifida
- 022 Myelodysplasia
- 023 Multiple Sclerosis
- 024 Quadriplegia
- 025 Paraplegia
- 026 Hemiplegia
- 027 Autism
- 028 Autonomic Dysfunction
- 029 Other Central Nervous System Conditions

CARDIOVASCULAR

- 030 Elevated Blood Pressure without Diagnosed Hypertension
- 031 Heart Murmur-Funct/Undiagnosed
- 032 Hypertension
- 033 Hypotension
- 034 Other Cardiovascular Disorders
- 035 Mitral Valve Disease
- 036 Aortic Valve Disease
- 037 Other Cardiovascular Conditions

RESPIRATORY

- 038 Significant Asthma
- 039 Chest wall deformity
- 040 Aspiration Pneumonias
- 041 Bronchopulmonary Dysplasia
- 042 Bronchiectasis

- 043 Cystic Fibrosis
- 044 Other Respiratory Conditions

GASTRO-INTESTINAL

- 045 Short gut
- 046 Pseudo Intestinal Obstruction
- 047 Malnutrition
- 048 Gastroesophageal (GE) Reflux
- 049 Malabsorption
- 050 Constipation
- 051 Crohns Disease
- 052 Ulcerative Colitis
- 053 Chronic Hepatitis
- 054 Chronic Pancreatitis
- Other gastro-intestinal conditions

ENDOCRINE/METABOLIC

- 056 Diabetes
- 057 Thyroid Disorder
- 058 Pituitary Disorder
- 059 Adrenal Disorder
- 060 Hyperthyroid Disorder
- 061 Hypopituitary Disorder
- Other Endocrine/metabolic disorders

ONCOLOGY

- 063 Leukemia
- 064 Hodgkin's Lymphoma
- 065 Non-Hodgkin's Lymphoma
- 066 Leg Long Bone Tumor
- 067 Arm Long Bone Tumor
- 068 Bladder Tumor
- 069 Brain Tumor
- 070 Metastatic Cancer
- 071 Other Cancers

MUSCULOSKELETAL/CONNECTIVE

- 072 Scoliosis
- 073 Osgood-Schlatter Disease
- 074 Other Bone Cartilage Disorder
- 075 Osteogenesis Imperfecta
- 076 Club Feet
- 077 Osteomyelitis
- 078 Juvenile Rheumatoid Arthritis
- 079 Other Arthritis

- 080 Sacral Agenesis081 Arthrogryposis
- 082 Femoral Anteversion
- 083 Tibial Torsion
- 084 Hip Dislocation
- 085 Other Skeletal Dysplasia
- Other musculoskeletal/connective tissue conditions

RENAL/GENITO-URINARY

- 087 Incontinence
- 088 Nephritis
- 089 Chronic Renal Failure
- 090 Neurogenic Bladder
- 091 Other Renal/genito-urinary Conditions

SENSORY SYSTEMS(EYE/EAR)

- 092 Mild Visual Impairment
- Moderate Visual Impairment
- 094 Severe Visual Impairment
- 095 Blindness
- 096 Refractive Error
- 097 Glaucoma
- 098 Other Visual Impairments
- 099 Mild Hearing Impairment
- 100 Moderate Hearing Impairment
- 101 Severe Hearing Impairment
- 102 Deafness
- 103 Chronic Recurrent Otitis Media
- 104 Structural Problem of the Ear
- 105 Other sensory system conditions

HEMOTOLOGY SYSTEM

- 106 Sickle Cell Anemia
- 107 Thalassemia
- 108 Iron Deficiency
- 109 Idiopathic Thrombocytopenia Purpura
- 110 Hemophilia
- 111 Other Blood Disorder

OTHER CONDITIONS

- 112 Bulemia
- 113 Anorexia Nervosa
- 114 Obesity
- 115 Recurrent Headaches

51. MedsCode: Specific medication

Length of Field = 2 Format: see codes below

MEDICATION CODES AND DEFINITIONS

Medication codes were developed in collaboration with staff from the Massachusetts Department of Public Health (MDPH), Connecticut Department of Education, committee and task force members and pharmacists from the Massachusetts College of Pharmacy, the MDPH Division of Food and Drug, and Children's Hospital.

Respiratory Medication

01 = Nebulizer

02 = Inhalers

03 = Oral asthma-related

04 = Other respiratory

Diabetic Medications

05 = Insulin

Psychotropic Medications

Stimulants:

06 = Ritalin (Generic = Methylphenidate) 07 = Dexedrine (Generic = Dextroamphetamine)

08 = Other Stimulants

Anti-depressants

09 = Prozac(Generic = Fluoxetine)10 = Elavil(Generic = Amitriptylene)11 = Zoloft(Generic = Sertraline)

12 = Clonidine

13 = Other anti-depressants

Mood Stabilizers

14 = Lithium Carbonate)

15 = Other mood stabilizers

Anticonvulsants

16 = Tegretol(Generic = Carbamazepine)17 = Depakene/depakote(Generic = Valproic Acid)18 = Klonopin(Generic = Clonazepam)19 = Dilantin(Generic = Phenytoin)20 = Phenobarbital(Generic = Phenobarbital)21 = Mysoline(Generic = Primidone)

22 = Other anticonvulsants

Anti-anxiety

23 = Librium (Generic = Chlordiazepoxide)

24 = Valium (Generic = Diazepam) 25 = Ativan (Generic = Lorazepam) 26 = Xanax (Generic = Alprazolam)

27 = Other anti-anxiety 28 = Other psychotropic

29 = Bowel Medications

30 = Bladder Medications

Antibiotics

31 = Amoxicillin

32 = Bactrim (Generic = Sulfamethoxazole/ Trimethoprim)

33 = Ceclor (Generic = Cefaclor)

34 = Erythromycin

35 = Penicillin (Generic = Penicillin VK)

36 = Other Antibiotics

37 = Musculoskeletal Medications

Cardiac Medications

38 = Lanoxin (Generic = Digoxin)

39 = Other cardiac Medications

Anti-Inflammatory Agents

40 = Aspirin (Generic = Aspirin) 41 = Motrin (Generic = Ibuprofen)

42 = Other anti-inflammatory agents

Other Medications

43 = Anticoagulants

44 = Epinephrine

* M.G.L. C.71, s 54B (Regulations 105 CMR 210.000)

52. MedsFreq: Medication Frequency

Length of Field = 1 Format: see codes below

1 = PRN, as needed basis

2 = Every day (long term greater than 1 month)

3 = Every day (intermediate term greater than 2 weeks)

4 = Every day (short term less than 2 weeks)

5 =Emergency use only

53. MedsAdmin: Medication Administration

Length of Field = 2 Format: see codes below

Licensed Personnel

01 = Registered Nurse

02 = Licensed Practical Nurse

03 = Nurse Practitioner

04 = Other licensed Professional (Certified Nurse Midwife,

Certified Nurse Mental Health Specialist, Physician)

Unlicensed Personnel

05 = Health Assistants

06 = Administrator (superintendent, principal)

07 = Teacher

08 = Day Care Worker

09 = Secretary

10 = Student (self-administration)

11 = Other

It is recognized that the reporting system will only include those medications students are taking that have come to the attention of the school.

54. InjuryActivity: Activity Associated with Injury

Length of Field = 2 Format: see codes below

The three injury-related elements are being collected specifically for needs assessment, program development and evaluation purposes. The elements and their fields have been reviewed by and are in accordance with recommendations made by the Massachusetts Department of Public Health Injury Control Program.

The following codes reflect the activity associated with the injury

01 = Baseball	02 = Softball
03 = Basketball	04 = Bicycling
05 = Classroom Activity	06 = Dancing
07 = Dodgeball	08 = Football
09 = Diving	10 = Field Hockey
11 = Ice Hockey	12 = Floor Hockey
13 = Jumping	14 = Kickball
15 = Climbing	16 = Crawling
17 = Running	18 = Sitting
19 = Ice Skating	20 = Roller Skating
21 = Sliding	22 = Swinging

23 = Swimming24 = Soccer25 = Ropes26 = Monkey Bars 27 = Tetherball28 = Volleyball30 =Weightlifting 29 =Walking 31 =Wrestling 32 = Throwing33 = Fighting34 =Cheerleading 35 = Trampoline36 = Tumbling37 = Cooking38 = Sewing39 = Track and Field 40 = Gymnastics41 = Industrial Arts42 = Lab Activity43 = Working (outside of school) 44 = Tire Swinging 55 = Other

55. InjuryBody Part: Injured Body Part

Length of Field = 2 Format: see code below

The following codes reflect that part of the body that was affected by the injury.

01 = Head	$02 - E_{VO}$	03 = Ear
01 – Head	02 = Eye	03 – Eai
04 = Nose	05 = Mouth/Lips	06 = Teeth
07 = Gums	08 = Face	09 = Jaw
10 = Chin	11 = Neck	12 = Clavicle
13 = Shoulder	14 = Upper Arm	15 = Elbow
16 = Forearm	17 = Wrist	18 = Hand
19 = Fingernail	20 = Finger	21 = Chest/ribs
22 = Back	23 = Abdomen	24 = Groin
25 = Genitals	26 = Rectum	27 = Pelvic/Hip
28 = Leg	29 = Knee	30 = Ankle
31 = Foot	32 = Toe	33 = Thigh

An occurrence is defined as an injury if it: 1) interrupts the student's normal or expected activity for that period to any significant degree, 2) causes any property damage or loss of more than \$5.00 in replacement cost and/or 3) can generate a litigation on behalf of the injured (taken from Taketa in "Student Accidents in Hawaii's Public Schools."

56. <u>InjuryType:</u> <u>Type of Injury</u>
Length of Field = 2 Format: see codes

The following type of injury codes should be used:

01 = Abrasion	02 = Amputation	03 = Bite
04 = Bruise	05 = Burn	06 = Contusion
07 = Crush Wound	08 = Dislocation	09 = Fracture
10 = Hematoma	11 = Laceration	12 = Pain
13 = Puncture Wound	14 = Sprain	15 = Strain
16 = Concussion	17 = Undiagnosed	18 = Other

57. <u>UserDefined</u>: <u>Measure to be defined by local district</u>: Currently Undefined

This field is intended as a place holder to be defined by the local school district. It can be any measure that the district is interested in collecting and analyzing that has multiple values per student.

DISTRICT-WIDE ELEMENTS

58. <u>TypSchDist:</u> The type of school district Length of Field = 1 Format: see codes below

The following coding will be utilized:

- 1 = Local Public School
- 2 = Independent Vocational School
- 3 = Academic Regional School
- 4 = Regional Vocational-Technical School
- 5 = Collaborative
- 6 = Non-Public Schools
- 7 = Other

59. KOC Kinds of Community

Length of Field = 1 Format: see codes below

The following basic codes, defined by the Massachusetts Department of Education, will be utilized to define KOC:

- 1 = Urban
- 2 = Suburban
- 3 = Rural
- 4 = Frontier

The frontier code was added to reflect the nature of some of the western states.

60. TypeSchProg Type of School Health Program by Building Length of Field = 1 Format: see codes below

The following codes will be used to categorized the type of school health program by building. More than one code may apply. For example, a high school could have both a traditional school health program as well as a school-based health center.

- 1 = Traditional
- 2 = Enhanced
- 3 = School-based Health Center

61. NurseRatio Nurse-to-Student Ratio by Building Length of Field = 5 Format: numeric

If the nurse-to-student ratio is 1 nurse to 800 students, the code = 00800. The field length of 5 digits is used as ratios as high as 1 nurse to 10.000 students have been noted.

62. NutritionBreak: Percentage of students in U.S. Department of Agriculture Free and Reduced Breakfast Program Length of Field = 3 Format: numeric

The percentage of students in the school district that participate in the free and/or reduced breakfast program. For example; if 20% of the students in the district participate in the program, the code 020 would be used. If no program is offered, the code would be 000.

63. NutritionLunch: Percentage of students in U.S. Department of Agriculture Free and Reduced Lunch Program Length of Field = 3 Format: numeric

The percentage of students in the school district that participate in the free and/or reduced lunch program. This should be coded the same as element 61.

MODEL SCHOOL HEALTH INFORMATION SYSTEM

UHDS Version 2.0

REFERENCES

- Bobak, M., Kriz, B., Leon, D.A., Danova, J.,& Marmot, M. Socioeconomic factors and height of preschool children in Czech Republic. American Journal of Public Health. 84, 11671170, 1994.
- Dutton, D.B. Socioeconomic status and children's health. <u>Medical Care</u>, <u>23</u>, 142-156, 1985.
- Haan, M.N., & Kaplan, G.A. The contribution of socioeconomic position to minority health. In Report of the Secretary's task force on black and minority health: crosscutting issues in minority health, ed. by M. Heckler. DHHS: Washington, D.C. 1985.
- Haan, M.N., Kaplan, G.A., Syme, S.L. & O'Neil, A. Recent publications on socioeconomic status and health. In Pathways to Health. In Pathways to Health, ed. by J.P. Bunker, D.S. Gomby, & B.H. Kehrer. The Henry J. Kaiser Family Foundation: Menlo Park, CA. pp. 319-420. 1989.
- Hahn, R.A. The state of federal health statistics on racial and ethnic groups. <u>Journal of the</u> American Medical Association. 267, 268-271. 1992.
- Mare, R.D. Socioeconomic effects on child mortality in the United States. <u>American Journal of Public Health</u>, 72, 539-547. 1982.
- Morrow, James, R., Jr., Falls, Harold, B., and Kohl, Harold, W. III. <u>The Prudential F1TNESSGRAM: Technical Reference Manual, Developed by The Cooper Institute for Aerobics Research and sponsored by the Prudential Insurance Company of America, 1994.</u>
- Murphy, J. Michael; Arnett, Hayley L.; Bishop, Sandra J.; Jellinek, Michael, S. and Joan Y. Reede. Screening for Psychosocial Dysfunction in Pediatric Practice: A Naturalistic Study of the Pediatric Symptom Checklist. Clinical Pediatrics. November, 1992: 660-667.
- Osborne, N.G., & Feit, M.D. The use of race in medical research. <u>Journal of American</u> Medical Association, 267, 275-279. 1992.
- Perrin, Ellen C.; Newacheck, Paul; Pless, I. Barry; Drotar, Dennis; Gortmaker, Steven L.; Leventhal, John; Perrin, James M.; Stein, Ruth E. K.; Walker, Deborah K. and

- Michael Weitzman. Issues Involved in the Definition and Classification of Chronic Health Conditions. <u>Pediatrics.</u> Vol. 91 No. 4 April, 1993: 787-793.
- Pope, Andrew M. and Alvin R. Tarlov. Disability in America: <u>Summary and Recommendations Toward a National Agenda for Prevention.</u> Washington D.C.: National Academy Press, 1991.
- Starfield, B.; Bergner, M.; Ensminger, M.; Riley, A.; Ryan, S.; Green, B.; McGauhey, P.; Skinner, A. and S. Kim. Adolescent Health Status Measurement: Development of the Child Health and Illness Profile. <u>Pediatrics</u>. Vol. 91 No. 2 February, 1993: 430-435.
- Starfield, B. & Budetti, P.P. Child health status and risk factors. Health Services Research. 19, 817-886. 1985.
- Stein, Ruth E. K.; Perrin, Ellen C.; Pless, I. Barry; Gortmaker, Steven L.; Perrin, James M.; Walker, Deborah Klein and Michael Weitzman. Severity of Illness: Concepts and Measurements. The Lancet. December 26, 1987: 1506-1509.
- Wise, P.H., Kotelchuck, M., Wilson, M.L. & Mills, M. Racial and socioeconomic disparities in childhood mortality in Boston. The New England Journal of Medicine, 313, 360366.1985.